EFFECTIVE HEALTH OUTREACH TO CULTURAL COMMUNITIES

GETTING THE WORD OUT

THE MEDTRONIC FOUNDATION
Getting the Word Out is a guide to effective outreach for health organizations. In particular, this guide is intended for patient support organizations that would like to make their information, referral, support and advocacy services more accessible to people from a variety of cultural communities.

A “cultural community” is a group of people bound together by culture — by common life experiences, behaviors and values. Cultural communities in the United States sometimes include individuals whose health is compromised due to differences in language, income, education, access to medical care, or other attributes of their cultural group.

Many patient support and advocacy organizations have made a special effort to approach, inform and mobilize cultural communities. Such outreach can be challenging. Organizations may encounter unexpected differences in values, health beliefs and behaviors. Effective outreach depends on knowing a community’s culture. Such cultural familiarity can help members of an organization plan outreach and program strategies that will be relevant and appropriate.

Why has The Medtronic Foundation published this guide? Medtronic is a world leader in medical technologies. Through its Foundation, particularly the Foundation’s Patient Link grant program, Medtronic is committed to empowering all people to live healthy, productive lives. Getting the Word Out is designed to be of particular assistance to groups participating in Patient Link, but it will be useful to a variety of people and groups committed to patient empowerment.

How to use this booklet
Getting the Word Out is divided into four sections:

  Why Get the Word Out?—an introduction to cultural communities and why they matter;
  How to Get the Word Out — a planning guide and list of strategies you may want to consider;
  Tips and Techniques — suggestions from the experts; and
  Readings and Resources — for further information.

We suggest you read through the entire guide before deciding whether and how to incorporate its ideas into your work.

We hope that Getting the Word Out will be helpful to you, but we know there is much left unsaid. So please — let us know what you think, what has worked for you, and what else you would add to help others get the word out. (Send your comments to Marty Cushing, Coordinator, Patient Link, The Medtronic Foundation, 612-879-5973, or mcushing@real-time.com)
A word about wording
One of the first challenges for anyone working with diverse populations is the dilemma of “what do we call each other?” People in the United States who are not of European ancestry can be “minority group members” or “people of color.” They can be “black” or “African American,” “Latino,” “Hispanic,” “Chicano” or “Mexican American” — just to name a few of many possible terms. What’s preferable? Sometimes it’s hard to know. A good place to start are the names generally accepted as the formal reference to these groups: African American, Asian or Pacific Islanders, American Indian or Alaska Natives, and Hispanic.

In this publication, we’ve used a variety of names for cultural communities, selecting the name that makes the most sense in context, or the one that seems the most respectful.

In referring to a cultural community, it’s obviously best to use the names that community prefers. The same goes for individuals. As a rule of thumb, if you’re unsure about terminology, it’s simplest and safest just to ask.

II. Why Get the Word Out?
You’re the director, program coordinator, or information manager for a patient advocacy group. You work hard providing information, support, advocacy and referrals to the people who contact your organization. You feel passionate about the importance of informing people about a particular disease or condition — so that they can prevent it, know how to treat it, and know how to live with it. You’d like to get the word out. You try to reach as many people as you can.

But unless you’ve given serious thought to who is targeted by your outreach efforts, chances are you’re missing some of the very people you could most help. The reasons for this are many, and complex, but one of the central reasons is culture.

Culture is a shared way of doing things that are learned by a group of people. A “cultural community” is a group of people linked together through a common sense of belonging or membership. People share values, beliefs, and ways of doing things.

Anthropologists and sociologists tell us that income level, educational attainment, race, ethnicity, and language create distinct subcultures within “mainstream” American culture. Each of these subcultures or cultural communities maintains its own specific health-related cultural beliefs and behaviors.

Cultural communities in America range from hip-hopping teens to train-hopping hobos, but each culture has its own explanations for the causes and treatment of ill health. This guide focuses to some extent on racial and ethnic cultural communities, but the secret to getting the word out to any community is the same: know the culture.

Cultural differences manifest themselves in tangible ways. For example, people from a given culture may not be comfortable talking about a problem involving the reproductive organs (this is often true of elderly people, regardless of culture). Cultures also have different ideas about how to talk frankly about serious or terminal illness. Some may choose never to mention the possibility of death directly. This becomes a challenge if your agency deals with a condition that has life-threatening implications.
Each of us has some beliefs and assumptions about health and illness that are ours alone, and others that we share with members of our cultural group. When one person experiences stomach pains, he may take an antacid. Another might consult an urgent care nurse. Others may fix an herbal tea, visit a shaman, or take acupuncture treatment. Some will do nothing, even when the pain becomes intense, perhaps because their culture views the expression of pain as a sign of weakness.

Our health behavior depends on the way we understand the cause of illness; what we think should be done about it; and whether we think anything can be done about it at all. Researchers call this culturally-influenced understanding an “explanatory model” — the way we make sense of the experiences of health and illness.

But what does knowing about a culture’s explanatory models have to do with getting your organization’s message to a hard-to-reach audience? Everything, if your message is about health-related beliefs and behaviors. Often, we try to educate or to convince people to act a certain way using our explanatory models, instead of theirs. If you want to help a community improve its health, you need to understand the way its community members think.

If you want to get the word out to a cultural community, knowing something about that community’s health care beliefs and behaviors is essential. In other words, one of the best ways to help people be healthier is to speak to them in ways that are culturally acceptable and relevant to them. It helps, for example, to know how the group generally prefers to receive information; whether they trust information given to them by a physician, or if they are more likely to believe something passed on by a community elder.

Does the community prefer one news medium over another? Cultural groups do have media preferences: some studies show, for example, that African Americans tend to get much of their news and health information from television or radio, rather than print.

Be aware, too, of the digital divide in planning for outreach methods. While computers seem pervasive in American culture, studies show that some communities are not as likely to rely on computerized media sources. Do community members generally have access to computers? (The answer may be surprising — according to one study, Hispanics have slightly more access to computers than whites.) Relying on websites to disseminate information may or may not be effective, depending on the audience.

These differences — beliefs about health, media preferences — are defining characteristics that can be used by you, the health educator. In a way, you have to think of yourself as a salesperson. As a “social marketer,” you are not “selling” soap — you’re promoting something far more valuable: your organization’s health information, resources and support. This is what you have to offer to someone — anyone, from any community — who wants to be the healthiest person they can be. As any good salesperson knows, if you want your marketing efforts to succeed, you must tailor your messages and your media to your audience.

Many health messages are not designed to reach beyond mainstream culture. Many messages are hard to understand — even for well-educated, English speaking individuals. A study of consumer health education, demand and delivery found that fully 40% of the American population found much health education “too difficult to be of value.” This is what makes getting the word out so challenging — and so essential.
Before you worry about HOW you get the word out, be sure you know WHY it’s important. In other words, make sure that your message is relevant to a given community. Know how your target community is affected by the disease or condition you focus on.

This is especially true if you are targeting a community of color or a low income community. In the U.S., there are significant differences in the way ill health affects different communities. Consider, for example, that on many Indian reservations, over half the population suffers from diabetes. Or that African American children of all income levels are hospitalized for asthma at three times the rate of white children. Consider that Latinos are more likely to be newly diagnosed with HIV infection than white people, but 1.5 times less likely to be treated with life-prolonging anti-retroviral therapies.

Disparities between whites and non-whites, and between wealthy and poor people occur in every major disease group: cardiovascular disease, stroke, cancer, diabetes, AIDS, mental illness and substance abuse. These gaps were recently documented in an overview report prepared by the Henry J. Kaiser Foundation of California, called *Racial and Ethnic Differences in Access to Medical Care* (see the Resources section of this booklet for a full citation).

According to that report (and many others), the causes of such disparities are complex, including genetic differences, environmental and occupational hazards, stress and lifestyle. But even when diagnosed at equal rates, racial and ethnic communities and low income groups face difficulties in accessing health care services and education. Poverty, lack of health care coverage and under-insurance (more prevalent in many minority communities) also affect access to information, prevention education, screening, treatment, referral to specialists, continued treatment and even pain relief.

So what does this mean for outreach? Diseases and chronic conditions that are prevalent in white, middle class populations are sometimes even more common among non-white, low income communities. Disparities in wealth are often paralleled by disparities in health. The need for advocacy, support and information services that are offered by patient support organizations like yours is likely to be greatest in the very communities that such organizations find hard to reach.

**An important note:** Disparities in health among communities are not always negative ones. Many cultural practices contribute to the health of a community, ranging from traditional diets that are low in fat, to emotionally and financially supportive bonds among members of extended families, or religious practices from which the faithful draw strength.

For example, despite a lack of prenatal care that parallels that of African-Americans, Latina mothers are far less likely to deliver low birth-weight babies with medical complications. Researchers hypothesize that this is because of healthy behaviors (avoidance of alcohol, non-smoking, high consumption of fruits and vegetables) that are more common in immigrant Latino cultures.

Researchers can pinpoint health disparities among communities, but they are also beginning to recognize the wealth of healthy traditions that other cultures have to offer. We all have much to learn from one another.
You've taken the first step. You've decided to expand your organization's outreach to cultural communities that have missed your messages in the past.

Now the work begins. Luckily, there are lots of excellent guides for you. We've tried to distill the advice from a number of these resources, and listed several in the back of this booklet for further reading.

There are three key steps to successful outreach. The first step is to gather background information about the community you'd like to work with, and assess your own organization. Second, you establish contacts and develop relationships with community members and organizations. Finally, you plan and implement an outreach program.

Obvious? Unfortunately not. Given the pressures of time, money, pending grant proposal deadlines and human nature, many organizations take these steps in reverse order — planning and implementing programs before establishing thorough contacts in a community; and making contacts before completing essential research. In your efforts to improve your organization's outreach, be sure to allot enough time for each step to ensure success.

**Step 1.**
**Learn about the community and assess your own organization.**
First of all, you'll want to learn as much as you can about the community you are targeting: its history; its primary language; members' health practices; how the group defines and explains health and illness.

There are many ways to gather data about a given community. Where to check? Try several of these approaches — not all of them will work with every community.

- Browse the stack at the public library or surf the Internet.
- Read medical and academic journal articles.
- Try local or cultural community newspapers.
- Consult informally with local academics, health and social service professionals and “key informants” from the target community.
- Attend community events and celebrations.
- Visit the community; learn its geography, key institutions and landmarks.

Look closely at the community you're targeting, but look just as closely at your own organization. Once you've gathered background information, present it to your staff, board and volunteers. Assess your own staff and board's willingness to give sufficient time and attention to new health outreach efforts. If people in your organization feel uncomfortable or unprepared to take on additional outreach, tackle that problem first. You may have to “sell” the idea of expanded outreach to resistant members of your organization.
How to check your organization’s readiness:

• Conduct an organizational assessment (see the checklist in the Readings section).
• Bring in trainers, consultants or health professionals from other communities for staff in-service.
• Examine the organization’s materials; what do your logo and mission statement imply about a commitment to outreach?
• Assess the agency’s staff and board composition: are members of the target community well represented? This last point can’t be stressed enough; there’s no point in claiming an interest in a community whose members are not present, ideally at every level, of the organization.

Step 2.
Build relationships with the community.
Before you plan a single event or translate even one of your agency’s flyers, you should work to build solid, useful relationships with key community members and institutions. Here’s where your research will pay off; if you’ve studied the community well, you’ll know who to contact.

There are many ways to learn more and establish initial contacts within a cultural community. Depending on your time and resources, you may want to:

• Participate as an interested observer in various community events or meetings.
• Talk informally with community members over coffee or lunch.
• Conduct more formal interviews.
• Meet with key people to develop a deeper understanding of their perspective.
• Develop a “case study” by focusing on a small group or family within the community.
• Conduct a focus group or survey.
• Locate or develop a network of professionals who provide similar services to the target community.

If you are making contacts with individual community members, don’t just link up with one or two of them. The people who are most willing to talk with you may not be as integrated into the community as those who are less immediately accessible, or they may be pursuing their own private agendas. Learn as much as you can by talking with as broad an array of people as possible.

Your list of formal and informal community leaders to contact might include:

• Local political leaders
• Community organization directors
• Government officials
• Community and social service workers
• Spiritual leaders: ministers, rabbis, shamans, elders
• Business leaders
• “Informal” community leaders
What to talk about? Ask about them, and listen. What are their ideas about health and illness? What are their concerns and priorities for their community? Later, you can explore how those priorities dovetail with your organization’s mission. Explain why your organization cares about the community — be clear about your agenda.

Don’t be surprised if your efforts to make contact and establish relationships are met with initial skepticism, distrust or even hostility. Many cultural communities have long histories of discrimination and exploitation by well-meaning outsiders. Many community members have personally experienced discriminatory treatment. Too often, research or even service organizations plan things to do to a community, rather than to do with them.

The time you spend developing relationships and gathering information will be invaluable when it comes to your final step. By being sincerely interested in a community, allowing members to get to know you, and investing the time to establish trust and rapport, you will increase the likelihood that your outreach efforts will be successful.

Step 3.
Plan and implement a program.
You have thoroughly researched the community and established a number of solid community connections. Now it’s time to plan a program. Here are some ideas for activities, with examples from non-profit agencies across the country.

Start with your own organization’s image.
Your organizational assessment may have revealed ways in which your agency could be more relevant and welcoming to members of cultural minorities. Check your logo, for example: does it suggest that the agency serves only one race or gender? Consider recording a telephone standard greeting in one or more of the major languages in your larger community. Look at your office decor: are there images on the walls that suggest everyone should feel at home?

In an effort to ensure calls from people at every income level, the Hypertrophic Cardiomyopathy Association installed a toll-free, 800 phone line.

Work closely with the target community.
Receiving advice and feedback from the target community is crucial to success. You may want to establish an advisory board of key individuals from the community. For an advisory board to be useful, however, it must be truly representative. Include recruits from a variety of segments of the target community, as well as agency staff and outside experts.

The National Multiple Sclerosis Society has begun a nationwide campaign to reach more Hispanic men and women. They will be guided by a national advisory board and several focus groups around the country to help them determine strategies and useful outreach techniques.

Hire staff from the community and recruit community volunteers.
One way to increase your expertise and build community relationships is to hire community members as managers and program staff.

After establishing a patient education center at a hospital serving the community, the Cancer Alliance for Research and Education assigned a Latina staff member to work there.
Work with community agencies to enhance their outreach efforts.
Team up with faith-based organizations, community agencies and groups of volunteers in your target community to ensure greater outreach. Share funding and other resources. This is collaboration at its best.

The Brain Injury Association of Minnesota hired an outreach worker to be shared among three Latino groups in one city, in order to provide specialized outreach about the effects of brain injury. The National Spinal Cord Injury Association, through its P.E.A.C.E. Project, works closely with The Center for Handgun Control, THINK FIRST Foundation, Concerned Black Men and churches in Washington, DC and Baltimore, Maryland to reach young African Americans.

Keep a case registry by race and ethnicity to track the prevalence of “your” disease or health condition in minority communities.
Registries are a common activity for patient support organizations, but many groups do not track cases by race or ethnicity. Such records can help, however, when you are making decisions about priority audiences. They can also help your organization make a case for additional funds to reach untapped audiences.

In order to find out more about the prevalence of MS by subgroups, the National Multiple Sclerosis Society is piloting the tracking of the race and ethnicity of callers to their information hotline. Information on ethnicity and primary language is being collected voluntarily.

Translate your organization’s materials — cautiously.
Translation may seem like an obvious first step, but should be undertaken cautiously. Be sure you have the program services or referrals to back up the implicit promise of print materials in another language. Furthermore, a good translation is hard to achieve. Hire a professional translator, someone who is fluent enough in English and the target language to be able to render the sense of your message, rather than translating word for word. If at all possible, avoid translation altogether, by developing materials from scratch with members of the community.

The Twin Cities Neighborhood Health Care Network, based in Minneapolis-St. Paul, assembled an advisory group of religious leaders, midwives and nurse practitioners from the Somali community to help develop a Somali guide to child spacing. The group offered ideas about content, design and language for the booklet before it was ever written.

Develop a media campaign.
Think carefully before spending time and money on media campaigns. They can be a seductive waste of resources, unless they are very well focused. Be sure to choose media that are preferred by the group you are targeting. (For example, African Americans are more likely to say that they get their health information from television and radio shows than whites.) Here’s where a board member or advisor with significant public relations experience, working hand in glove with your community advisory board, can be very helpful. Don’t forget to prepare for the increase in demand generated by your media campaign.

To heighten awareness in the black community, the National Stroke Association developed a media campaign using African American television actress Della Reese. They also placed print ads in Ebony and Black Diaspora magazines.
Capitalize on existing media resources.
Sometimes television news or drama shows will offer a lucky outreach opportunity you could never afford on your own.
The Cardiac Arrhythmias Research and Education Foundation hired a phone bank to help cope with the deluge of calls for information after the problem of sudden cardiac arrhythmia was featured on an episode of Chicago Hope on television.

Identify celebrity spokespeople.
In a celebrity-oriented world, the extra attention that a well-known person can bring to your organization can be invaluable.
The Parkinson's Action Network’s visibility jumped dramatically after actor Michael J. Fox publicly acknowledged his battle with Parkinson's; similar exposure was garnered when boxer Mohammed Ali went public.

Stage an educational event in the community.
Have a health fair — but make it fun. Double up with an existing community event (here's where your research pays off). Ask if you can have a booth at a community powwow, pride day, or ethnic holiday celebration. Or take advantage of other community institutions that offer credibility and access.
The National Stroke Association developed a program for children in schools to interview caregivers and elders about their experiences with high blood pressure and stroke.

Train community-based peer educators.
Health education research shows that peer educators — individuals who are bicultural or bilingual and indigenous to the community — are highly effective at delivering health outreach messages.
The National Spinal Cord Injury Association’s Peace Project uses teen gunshot victims in Washington, DC to educate other teens about spinal cord injuries and gun violence.

Link with policy-focused organizations to tackle health problems that have systemic roots.
Sometimes health education and support for individuals is not enough. It makes little sense, for example, to urge women to get regular screenings for cancer if transportation to a screening site is not readily available. You may find that one of the most effective strategies your organization can adopt is to lend its support to efforts to increase health care access in general.
The Interstitial Cystitis Association, National Asian Women’s Health Organization, Epilepsy Foundation, and National Black Women’s Health Organization are four of the many organizations that have joined with the Society for Women's Health Research to form the Alliance for Women in Clinical Trials.
Expanding outreach to cultural communities is not easy, but more and more health organizations are doing it successfully. Their experiences, along with advice from Medtronic’s Patient Link consulting agencies (listed in the “Resources” section), should help you avoid these common pitfalls and problems:

Q. We all know this kind of outreach is important, but our organization just doesn’t have the money.
A. Start small. Start where you are, with an assessment of your organization. Determine whether it is appropriate at this time to conduct outreach to another community. If yours is a very new organization, targeted outreach efforts may be premature. Concentrate on strengthening the agency first, building as diverse a board, staff and volunteer corps as you can. In building that infrastructure, you can always build in programs and channels that will enable outreach later on.

Q. I don’t know anybody from a cultural community. Where do I start?
A. Pick up a community newspaper. Get help from one of the consulting organizations listed in the Resources section. Go to networking meetings. Walk through the neighborhood, visiting with community residents and stopping in at local stores. You may have to be bold, and you may risk a rebuff or two, but a sincere effort to learn more about a community will eventually be rewarded.

Q. Who within the organization should lead our outreach effort?
A. For your organization’s efforts to succeed in the long run, you need to have buy-in from the top down. Board awareness and approval is critical. But research, making contacts and planning can fall to the person who feels most passionate about the target community and has already made an effort to get familiar with it. Capitalize on that caring. The staffer or volunteer who has shown initiative may develop especially creative approaches.

Q. I’d like to learn more about the relationship between culture and health. What can I read for a quick intro to a variety of cultures?
A. Check the readings listed in the back of this guide; but remember that there is no “cookbook” that will provide recipes for outreach to specific communities.

Q. My board is not interested in outreach of this nature. How can I get them interested?
A. You may simply have to wait until you can recruit new board members. In the meantime, committee members and volunteers can be very influential; try to recruit people from the target community who can be especially persuasive. One strategy is to invite community members to meet with your board in informal, brown-bag lunch and talk sessions.
Q. Should I start with translating our materials?

A. Translation is a complex, sophisticated process. If at all possible, leave the translation or development of health education materials to a professional. Unless he or she is highly skilled, don’t just let a volunteer translate your brochure word-for-word. Remember, too, that culture is not just language. Cultural barriers are often misdiagnosed as merely linguistic barriers and are thought to be addressed by the provision of interpreters and translation. But cultural differences go far beyond language to include beliefs, assumptions, values, practices, and world views.

Q. In finding out about a cultural community, I worry about the risk of stereotyping individual members of that community.

A. This is a reasonable concern. We all try to predict an individual’s behavior based on our observations about other, similar individuals. But try to keep in mind the distinction between a generalization (observing that many Hmong families are large) and a stereotype (assuming that all Hmong families are large, just because many are.)

Q. All this talk about “marketing” sounds crass to me. We’re in the business of helping people, not selling to them.

A. You can’t help someone unless he or she is aware of the assistance you have to offer. By “marketing” your organization to cultural communities, you are simply empowering them. They can still choose whether or not to avail themselves of your services.

Q. What’s the one thing we could do that would enhance our profile within a cultural community?

A. This isn’t often practical, but if your agency is considering a move, or opening a satellite office, relocate to the heart of the community you seek to reach. Your physical presence within the community will speak volumes, and will make outreach practically inevitable.

Q. How can I get more bang for the buck with our media campaign?

A. Knowledge and awareness are useless unless they affect behavior. Awareness campaigns should be followed by community-level education. You can reach a lot of people with a series of public service messages broadcasting your agency’s phone number. But unless you have culturally relevant services to offer people who call, you may as well not bother advertising your existence. If you advertise in Spanish, someone who speaks Spanish should be available to answer calls. Non-Spanish-speaking staff can be trained to read a short sentence saying that someone who speaks Spanish will return the call shortly.
V. Selected Readings

Reports

Key Facts: Race, Ethnicity and Medical Care, The Henry J. Kaiser Family Foundation. October 1999. A summary of the report listed above. Copies available through the Foundation website, www.kff.org or by calling the publication request line, 1-800-656-4533.


Consumer Health Information Demand and Delivery (Meta Analysis Project), 1994 Office of Disease Prevention and Health Promotion, Public Health Service, Centers for Disease Control, National Library of Medicine. Available at public libraries in the government documents section.


Books and Periodicals
American Demographics magazine. Up-to-date census-based information about communities in the U.S. Stamford, CT. Available in many libraries; call 1-800-529-7502 for subscriptions.


The Spirit Catches You and You Fall Down, 1998 Anne Fadiman, Farrar Strauss & Giroux, New York. A true story depicting the colliding worlds of Western Medicine and Hmong culture.
For information on consumer health and medicine, including increasing information provided for specific communities, consult a health resource website such as www.WebMD.com.